DOCUMENT RESUME

ED 262 505 EC 180 913

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TITLE	What Is Down Syndrome? 1984 Digest.
INSTITUTION	ERIC Clearinghouse on Handicapped and Gifted Children, Reston, Va.
SPONS AGENCY	National Inst. of Education (ED), Washington, DC.
PUB DATE	84
CONTRACT	400-81-0031
NOTE	3p.
AVAILABLE FROM	ERIC Clearinghouse on Handicapped and Gifted Children, 1920 Association Dr., Reston, VA 22091 (one free copy).
PUB TYPE	Guides - Non-Classroom Use (055) -- Information Analyses - ERIC Information Analysis Products (071)
EDRS PRICE	MF01/PC01 Plus Postage.
DESCRIPTORS	Child Development; Curriculum; Definitions; *Downs Syndrome; Educational Needs; Elementary Secondary Education; Genetics; Incidence; *Student Characteristics
IDENTIFIERS	ERIC Digests

ABSTRACT

The digest presents an overview on Down Syndrome. The history of the term is traced to its association with Dr. John Langdon Down who first described the condition in 1866. Characteristics of Down Syndrome are noted, including mental retardation, short stature, epicanthic folds, reduced muscle tone, joint hyperflexibility, and premature aging. Causes of the genetic abnormality are reviewed as are prevalence rates. Ways in which Down Syndrome affects development are covered, including deficient social skills and delayed language development. It is suggested that education programs include infant stimulation and curriculum organized around long term skill sequences designed to promote independent functioning skills. The ability of amniocentesis to identify the condition prenatally is discussed. The digest concludes with a listing of references and resources on the topic. (CL)

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1984
DIGEST

WHAT IS DOWN SYNDROME?

What is now referred to as Down Syndrome was originally known as mongoloidism because of the similarities in facial characteristics to people of the Mongol race. The term Down Syndrome is taken from the name of the English physician, Dr. John Langdon Down, who is credited with first describing the condition in 1866. It was not until 1959 that the actual chromosomal abnormality associated with the syndrome was discovered. Dr. Jerome Lejuene found that individuals with Down Syndrome possessed additional genetic material in their cells, usually an extra chromosome. Instead of having 46 chromosomes in each cell (22 pair of autosomes or non-sex chromosomes and one pair of sex chromosomes, xx in females, xy in males), Down Syndrome individuals have 47 chromosomes, with the extra chromosome being a small piece of #21 chromosome. The term Trisomy 21 is therefore used to describe this configuration of three #21 chromosomes. About 95% of all individuals with Down Syndrome have Trisomy 21.

What are the Characteristics of Individuals with Down Syndrome?

In general, individuals with Down Syndrome possess a majority, but not necessarily all, of the following characteristics:

- mental retardation, usually in the moderate range
- short stature
- flat, broad face with small ears and nose
- short, broad hands with in-curving little fingers
- upward slanting of the eyes with folds of skin (epicanthic folds) at the inside corner of the eye
- small mouth and short roof which, combined with low muscle tone, may cause the tongue to protrude intermittently and furrow. This may contribute to later articulation problems
- close set, deep eyes that are strabismic (cross-eyed)
- delayed eruption of teeth, with teeth being small, abnormally shaped and aligned
- A Simian, or single, crease across the palm
- wide space between first and second toe
- reduced muscle tone (hypotonia)
- hyperflexibility of joints
- small skull with a flattened back of the head and "soft spots," which may be larger than the normal infant's, and close at a later age
- heart defects (25-35%)
- increased susceptibility to upper respiratory infections, hepatitis, shegellosis, inflamed tonsils, gum inflammation, and gum recession
- incomplete or delayed sexual development
- blockage of upper intestinal tract or gross malfunctioning of the lower large bowel (less than 5%)
- leukemia (1%)
- premature aging.

What Causes the Genetic Abnormality?

In Trisomy 21, the extra chromosome may come from the egg or the sperm. It is suspected that during cell division of the egg or the sperm, the two #21 chromosomes do not separate properly and one cell will therefore have an extra #21 chromosome which later, if united with a normal cell, may lead to Trisomy 21. What causes this improper cell division is unknown. Things such as viral infections, hormonal abnormalities, X rays, and certain drugs are being investigated as potential causal factors. A small number of cases are genetic in origin. This can be determined through genetic counseling.

How Often Does Down Syndrome Occur/Reoccur?

Down Syndrome accounts for approximately 10% of the retarded individuals with moderate and severe forms of mental retardation. Down Syndrome occurs once in every 1,500-2,000 births when the mother's age is below 25; once in every 400 births when the mother's age is over 35; once in every 40 births when the mother's age is over 45. A mother with a child who has Down Syndrome, has a one in 25 chance of having another Down Syndrome child. Siblings of Down Syndrome children have the same risk of having a child with Down Syndrome as does the general population unless the disorder is of genetic origin.

How Does Down Syndrome Affect Development?

All areas of development are usually delayed in a child with Down Syndrome. The poor muscle tone influences all aspects of gross and fine motor development but the tone can be improved with physical therapy, a consistent, structured program of physical activity, and an ongoing weight maintenance plan. Likewise, language development is delayed due to muscle problems and cognitive limitations; a structured stimulation program and language therapy can help to improve skills.

Since mental retardation inevitably occurs in children with Down Syndrome, higher integrative abilities such as the ability to abstract, and to form concepts are usually impaired. Some Down Syndrome children function within the mild range of mental retardation; however, the level of intelligence in most cases ranges from moderately to profoundly retarded. Most individuals with Down Syndrome can learn to care for themselves, function within a community, and secure some form of employment, either in a workshop or the competitive job market.

The social skills of individuals with Down Syndrome are usually less deficient than are their cognitive skills and statistics indicate fewer instances of severe emotional/behavioral disturbance in these individuals.

What Should be Included in Education Programs?

Since Down Syndrome is identifiable at birth in the majority of cases, an infant stimulation program, either in the home or in a center-based setting, affords both the child and the parent an opportunity to learn and grow. The Education of All Handicapped Children Act (P.L. 94-142) ensures each child the right to a free appropriate public education program until age 21.

The content of the school program should be closely aligned to the child's immediate needs and prior experiences. The curriculum should focus on communication skills, social skills, self-help skills, motor development, coping successfully with the physical environment, and the enrichment of sensory experiences. It should be organized around long term skill sequences designed to facilitate the acquisition of necessary independent functioning skills. As an adult, the individual should have the skills necessary to live in the community, with some form of supervision, and secure vocational training and/or employment.

Since individuals with Down Syndrome generally age prematurely, they are prone to the problems of aging at an earlier age. Rates of development vary from individual to individual; however, as with any human being, education, stimulation and the opportunity to participate in a variety of experiences facilitate all areas of development and assist the individual in becoming more able to deal with the daily environment in a meaningful way.

Can Down Syndrome be Diagnosed Before Birth?

Down Syndrome is the most common of the forms of mental retardation that can be identified during the prenatal and perinatal periods. Amniocentesis, which involves inserting a needle through the mother's abdomen and withdrawing some amniotic fluid (fluid surrounding the fetus), can be performed around the 14th week of pregnancy. The fluid can be subjected to chemical tests and the chromosomes analyzed. In this manner, Down Syndrome can be detected. Amniocentesis is often recommended if there is a history of Down Syndrome in the family or if the woman is over 35 or 40 years of age.

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Carter, C. (1975). *Handbook of mental retardation syndromes* (3rd ed.). Springfield: Charles C Thomas.

Pueschel, S. & Rynders, J. (Eds.). (1982). *Down Syndrome: Advances in biomedicine and the behavioral sciences*. Cambridge, MA: Ware Press.

Robinson, N. & Robinson, H. (1976). *The mentally retarded child* (2nd ed.). New York: McGraw-Hill.

RESOURCES

National Down Syndrome Congress, 1640 W. Roosevelt Rd., Chicago, IL 60608 (312/226-0416).

An information packet is available free of charge. A newsletter is published ten times per year—subscriptions $15 a year. An annual convention is also held which should be of interest to professionals.

Association for Retarded Citizens—United States, P.O. Box 6109, Arlington, TX 76011 (1/800-433-5255).

ARC publishes literature about Down Syndrome and directs people to local units across the country, some of which have Down Syndrome committees.

National Down Syndrome Society, 70 W. 40th St., New York, NY 10018 (212-764-3070).

An information packet, including "Your Baby Needs You Even More," is available free of charge. Annual mailings are sent to people who have requested the information packet. A film, "Gifts of Love," is also available.

The National Information Center for Handicapped Children and Youth, P.O. Box 1492, Washington, DC 20013.

An information packet on Down Syndrome or any other handicapping condition is available free of charge. Also ask to be added to the Center's mailing list. Information about local resources for special children is also provided.

Cara—Growing with a Retarded Child by Martha Moraghan Yablow. Available from Temple University Press, Broad & Oxford Streets, Philadelphia, PA 19122. $24.95 cloth; $12.95 paper plus $1.50 postage & handling.

Down Syndrome: Papers and Abstracts for Professionals, 104004 Leslie Court, Silver Spring, MD 20902. $5.00 per year; quarterly newsletter.

An Overview of Down Syndrome (1983) by Siegfried M. Pueschel. Available for $1.50 from ARC—United States, P.O. Box 6109, Arlington, TX 76011.

This introductory booklet provides basic information on Down Syndrome and sources of more information.

A Reader's Guide for Parents of Children with Mental, Physical, or Emotional Disabilities—1983 Update. Single copies available free from National Maternal and Child Health Clearinghouse, 3520 Prospect Street, N.W., Ground Floor, Washington, DC 20057 (202-625-8400).

Special Kids Make Special Friends (1984) by Debra Buchbinder Shalom. Available from An Association for Children with Down Syndrome, 2616 Martin Avenue, Belmore, NY 11710 (516-221-4700).

Jon O.: A Special Boy by Elaine Ominsky. Available from Prentice-Hall Publishers, Englewood Cliffs, NJ 07632 (201-592-2000).

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The National Institute of Education

This publication was prepared with funding from the National Institute of Education, U.S. Department of Education under contract no. NIE-400-81-0031. The opinions expressed in this report do not necessarily reflect the positions or policies of NIE or the Department of Education.